Challenges of embracing a rights-based approach to development when working with people affected by leprosy

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Background

- ‘All human beings are born free and equal in dignity and rights’ UNDHR
- Principles and Guidelines for the Elimination of Discrimination against People Affected by Leprosy and their Family Members.
- Stigma and human rights violations remain.
- Need for rights awareness and mobilisation to challenge injustice.
Learning from the 17 challenges

‘Incidents of engagement documents’
‘Learning reflection’
Some of the Major Challenges

Fatalism

“Leprosy is my fate; no one can help me. I have to live with my fate. “

Self stigma and lack of self-belief

- Internalised stigma.
- Feel not worthy to be counted as human beings
- Consider themselves outcasts and withdraw from society.
Some of the Major Challenges

Culture of begging and lack of interest in rights issues
- Cannot see beyond their immediate needs
- Begging can be very lucrative

Illiteracy and lack of education
- Need for support to engage in advocacy activities such as memorandums, documenting evidence of discrimination

Lack of strong leadership
- Lack of vision
- Focus on day to day survival rather than development
Some of the Major Challenges

Lack of unity among leprosy colony members
- Political and religious divisions
- Need to unite to achieve a common goal

Lack of knowledge of rights and government social welfare schemes
- Little or no knowledge of schemes

Lack of understanding of government processes
- Difficulty understanding formal processes needed to access entitlements
- Not knowing who to approach or how
Some of the Major Challenges

Unwillingness to accept leaders affected by leprosy from outside their colony
- Colony leaders wanting to hold power and take credit for change

Promoting self interest
- Personal rather than community gain

Existing leprosy people’s organisations do not use a rights based approach
- Welfare focused
- Perpetuating dependence
- Lack of understanding of what can be achieved through advocacy
Some of the Major Challenges

Difficulty including people affected by leprosy from outside the colonies in advocacy

- Unwillingness to declare status
- Fake addresses/numbers
- Geographical spread

No faith in community development workers

- Unmet promises, lack of trust

Lack of priority for changing legislation

- Focused on survival
Some of the Major Challenges

Lack of leprosy/human rights awareness among general community
- Fear
- Lack of knowledge of leprosy facts
- Tradition deeply ingrained

Lack of media interest
- Commercially minded rather than social justice focused
- Leprosy not a ‘sexy’ issue

Charity focus of NGOs/faith-based organisations involved in leprosy
- Perpetuating dependence
Conclusion

• Reducing stigma (including self-stigma) and discrimination will, no doubt, be a long process.
• Recognition of the challenges is the first step in the process of people affected by leprosy accessing their rights and entitlements.
• These 17 challenges need to be addressed by community development programmes, if people affected by leprosy are going to move from dependence on charity to being empowered to challenge injustice.
• Learning from reflection on the ‘incidents of engagement’ provides insight not only into the challenges experienced but also on potential approaches for intervention.
• Focus should not just be on attitude change of the general community to promote social integration there needs to be a focus on changing the mindset of people affected by leprosy themselves – the key is working with the youth.